Renaming schizophrenia: a Japanese perspective

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In order to contribute to reduce the stigma related to schizophrenia and to improve clinical practice in the management of the disorder, the Japanese Society of Psychiatry and Neurology changed in 2002 the old term for the disorder, "Seishin Bunretsu Byo" ("mind-split-disease"), into the new term of "Togo Shitcho Sho" ("integration disorder"). The renaming was triggered by the request of a patients' families group. The main reasons for the renaming were the ambiguity of the old term, the recent advances in schizophrenia research, and the deep-rooted negative image of schizophrenia, in part related to the long-term inhumane treatment of most people with the disorder in the past. The renaming was associated with the shift from the Kraepelinian disease concept to the vulnerability-stress model. A survey carried out seven months after renaming in all prefectures of Japan found that the old term had been replaced by the new one in about 78% of cases. The renaming increased the percentage of cases in which patients were informed of the diagnosis from 36.7% to 69.7% in three years. Eighty-six percent of psychiatrists in the Miyagi prefecture found the new term more suitable to inform patients of the diagnosis as well as to explain the modern concept of the disorder. The Japanese treatment guideline for "Togo Shitcho Sho" was developed in 2004 under the framework of the vulnerability-stress model.

Key words: Schizophrenia, stigma, renaming, vulnerability-stress model

Schizophrenia is one of the leading causes of disability-adjusted life years (DALYs) lost and years of life lived with disability in 15-44-years-olds in the world (1). In Japan, 260,000 patients with schizophrenia were treated every day in 1999, and 202,012 were admitted to a mental hospital in 2002. Patients with schizophrenia represented 53% of all inpatients with mental disorders in 2002, and their mean duration of hospitalization was 363.7 days in the same year.

After the 2001 World Health Day, a series of initiatives have been implemented in Japan to promote a community-based care instead of hospital-centered care. While the WPA Global Programme against Stigma and Discrimination because of Schizophrenia (2) was initiated in 1996, the Japanese Society of Psychiatry and Neurology (JSPN) had started its efforts to tackle the misunderstandings and deep-rooted prejudices about schizophrenia already in 1993. Part of these efforts has been the replacement of the old Japanese term for schizophrenia – "Seishin Bunretsu Byo" (i.e., "mind-split-disease") – by the new term "Togo Shitcho Sho" ("integration disorder"). The new term was approved by the JSPN General Assembly in August 2002. This paper reviews the impact of the renaming on psychiatric practice in Japan.

BACKGROUND OF THE RENAMING OF THE JAPANESE TERM FOR SCHIZOPHRENIA

In 1993, the National Federation of Families with Mentally Ill in Japan (NFFMIJ) requested the JSPN to replace the term "Seishin Bunretsu Byo" by a less stigmatizing one. The JSPN Committee on Concept and Terminology started to examine the request in 1995. After a series of questionnaire surveys, symposia and workshops at the annual JSPN meeting, it was decided to change the old term into a new one, provided that: a) the change did not result in any disadvantage to the patients, and b) the term conveyed the concept that schizophrenia is a disorder defined by a clinically significant syndrome, but not a disease defined by a specific etiology, symptomatology, clinical course and pathological findings. The Committee examined several alternatives, and finally selected the term "Togo Shitcho Sho" ("integration disorder"). After surveys involving the NFFMIJ, the citizens and JSPN members on the appropriateness of the new term and a public hearing, the JSPN Board accepted the new term, which was finally approved by the JSPN General Assembly in August 2002.

REASONS FOR THE RENAMING

The first reason for the renaming was the need to remove the harmful impact of the diagnosis with the old term on the patients and their families. In Japan, many psychiatrists hesitated to inform the patients of the diagnosis of schizophrenia using the old term, because of the possible negative consequences on treatment adherence and outcome. For instance, Ono et al (3) reported in 1999 that 52% of JSPN Council members informed their patients of the diagnosis of schizophrenia only occasionally on a case-by-case basis, and only 7% of them informed all their patients of the diagnosis. Thirty-seven percent of the members informed only the patients' families. On the other hand, Koishikawa (4) reported in 1997 that only 16.6% of the patients and 33.9% of their families were able to report correctly the diagnosis. This means that approximately 167,000 patients with schizophrenia in Japan spent in a psychiatric ward more than one year (on average) without knowing what their diagnosis was. These findings indicate a serious communication gap among psychiatrists, patients and their families, which makes collaborative treatment and psychoeducation more difficult.

The old term identified the patient as a person with a disorganized personality even after recovery or full remission. That is, once the diagnosis of "Seishin Bunretsu Byo" was

made, the patient was usually regarded as an essentially ill person throughout his or her life. This was the main reason why the NFFMIJ required the JSPN to change the old term.

Moreover, in many Japanese textbooks of psychiatry up to the 1970s, "Seishin Bunretsu Byo" was essentially described following the concept of dementia praecox. It was characterized by a poor prognosis and a chronic process of deterioration, eventually leading to decay of personality. It required the physician to evaluate how the process of deterioration was progressing. Not surprisingly, according to a survey carried out in 1996 (5), 77.3% of JSPN Council members thought that the general image of schizophrenia in the community was that of an untreatable disease.

However, since the 1970s, Bleuler (6), Harding et al (7), Ciompi (8) and others reported in long-term outcome studies of schizophrenia that a majority of patients may recover. Ciompi proposed a complex bio-psychosocial view of schizophrenia (9) based upon the vulnerability-stress model (10). Thus, schizophrenia is currently conceptualized as a clinically significant syndrome, whose etiology and pathophysiology are not yet firmly established.

Along with the modern advances in neurosciences and the development of pharmacological and psychosocial interventions, the investigation of the biological risk factors for schizophrenia and the achievement of social integration of the patients are two main themes of schizophrenia research in Japan. These recent research advances also contributed to convince the JSPN to abandon the old name as well as the old concept of the disorder.

A further reason for the stigmatization attached to the old term is the history of inhumane treatment of patients with "Seishin Bunretsu Byo" in the first half of the 20th century. In those days, families were obliged to take custody of these patients by a special legislation ("Seishin Byo Sha Kango Ho"). Several patients were confined to a small isolated room or a hut under restraints. This law was replaced in 1950 by a Mental Hygiene Law, subsequently revised in 1965. A Mental Health Law and a Mental Health and Welfare Law were then implemented in 1987 and 1995, respectively. After this continuing effort, psychiatric treatment and care in today's Japan has improved remarkably. Contrary to this, the stigma caused by this long history of exclusion and inhumane treatment remains deeply rooted even now.

The new term for schizophrenia ("Togo Shitcho Sho") refers to the vulnerability-stress model, and implies that the disorder may be treated and that recovery is possible if a combination of advanced pharmacotherapy with appropriate psychosocial intervention is used. In Japan, we use this model for the investigation of biological vulnerability for schizophrenia and in clinical practice.

SPREAD OF THE NEW TERM AFTER RENAMING

After the official approval of the new term, the frequency of appearance of the old and new term in reports from mental hospitals was examined monthly in the Miyagi Prefecture and Sendai City (n = 1,944). Six months after the renaming, the new term was used in 85.5% of cases in Sendai City and 74.5% of cases in the Miyagi Prefecture. A similar survey was carried out in all prefectures of Japan seven months after renaming. The new term was used in an average of about 78% of cases in these reports (n = 17,108) (11).

Nishimura and Ono (12) reported that the percentage of cases in which patients were informed of the diagnosis increased from 36.7% in 2002 to 65.0% in 2003 and eventually to 69.7% in 2004. They also reported that 98.0% of those who usually informed the patient of the diagnosis used the new term in 2004, compared to 68.0% and 86.0%, respectively, in 2002 and 2003. However, 35.9% of them also used the old term concomitantly. Thus, the use of the new term clearly increased the frequency with which patients were informed of the diagnosis.

In our survey of 136 members of the Miyagi College of Psychiatrists carried out 13 months after the renaming (11), 86% of the respondents found the new term easier to inform patients of the diagnosis as well as to explain the concept of the disorder. Eighty-two percent of them found the new term more suitable to obtain consent to treatment from patients, useful to improve treatment compliance, effective to reduce stigma, and promising for achievement of social integration.

The College of Chairman Psychiatrists of Japan published in 2004 the Practice Guideline for the Treatment of Schizophrenia (13) using the new term and the vulnerability-stress model. This guideline recommends: a) a community-based care instead of hospital-centered care; b) a multi-axial assessment based on the DSM-IV-TR for the formulation of a treatment plan including medication and psychosocial intervention; c) a treatment plan adequately formulated for acute, remission and stable phases; d) the establishment of a therapeutic alliance including psychiatric social workers.

The above process is to be regarded as part of the WPA Global Programme against Stigma and Discrimination because of Schizophrenia. It kindled a series of anti-stigma activities in many areas of Japan (14) and contributed to new policies implemented by the government (15). It may represent a useful model for other countries worldwide.

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